



**CREATING A MORE SECURE FUTURE**  
**FOR**  
**KENTUCKIANS WITH AUTISM SPECTRUM DISORDERS**

ANNUAL UPDATE

**The Kentucky Council on Developmental Disabilities**

Submitted in Accordance with House Bill 296 to:

**Governor Steve Beshear**  
**And the General Assembly**  
**October 1, 2009**



The Commonwealth of Kentucky

Cabinet for Health Services

On Behalf of



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**THE KENTUCKY COUNCIL ON DEVELOPMENTAL  
DISABILITIES**

Presents:

**2009 ANNUAL UPDATE**

An Annual Submitted in Accordance with House Bill 296 to:

Governor Steve Beshear

And the General Assembly

**October 1, 2009**



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September 18, 2009

The Honorable Steven L. Beshear  
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Dear Governor Beshear,

Pursuant to house Bill 296, the Kentucky Council on Developmental Disabilities has been granted the authority and responsibility to monitor the implementation of the comprehensive state plan set forth in the Report until October 1, 2015. Enclosed please find the bi-annual update and recommendations of the Kentucky Commission on Autism Spectrum Disorders State Plan of which the Kentucky Council on Developmental Disabilities has had the opportunity to monitor.

The passage of BR 121 this upcoming 2010 Legislative session would have a positive affect on many individuals with Autism Development Disorders and their families. The Council looks forward to monitoring the future success of BR 121 and of the State Plan's overall achievement.

Sincerely,

*Donna Brinkman*

Donna Brinkman, Chairperson  
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## **INTRODUCTION**

According to the Autism Society of America

- 1 to 1.5 million Americans<sup>2</sup>
- Fastest-growing developmental disability
- 10 - 17 % annual growth
- \$90 billion annual cost<sup>3</sup>
- 90% of costs are in adult services<sup>3</sup>
- Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention<sup>3</sup>
- In 10 years, the annual cost will be \$200-400 billion<sup>4</sup>
- . Autism affects all races, ethnic groups, and socioeconomic levels.

Reference: <http://www.autismsociety.org>, (7/2009)

Kentucky's population according to the 2000 census was 4,058,633. Using the prevalence data of 1/150, the number of individuals with ASD in Kentucky would be over 27,000.

### **Autism Spectrum Disorder Defined**

Autism Spectrum Disorder (ASD) is the name given to describe the wide range of behaviors amongst the Autistic population. Children with autism are less able to interact with the world as other children do.

Typically they have deficits in three key areas:

- Verbal and non-verbal Communication
- Social awareness and interactions
- Imaginative play (variable interests and behaviors). (Reference: Diagnostic and Statistical manual of

Mental Disorders (DSM-IV), 6/2007)

Autism is defined in the Diagnostic and Statistical manual of Mental Disorders (DSM-IV). Autism Spectrum Disorder (ASD) is the name given to describe the wide range of behaviors amongst the Autistic population. Children with autism are less able to interact with the world as other children do. Typically they have deficits in three key areas:

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- Social awareness and interactions
- Imaginative play (variable interests and behaviors). (Reference:

[http://www.autism.net.au/Autism\\_Definition.htm](http://www.autism.net.au/Autism_Definition.htm), (7/2008)

Autism is a complex developmental disability that causes problems with social interaction and communication. Symptoms usually start before age three and can cause delays or problems in many different skills that develop from infancy to adulthood. (Reference: [www.nichd.nih.gov/health/topics/asd.cfm](http://www.nichd.nih.gov/health/topics/asd.cfm), 10/2008) This complexity leads individuals who are diagnosed with ASD, their families and other caregivers to routinely characterize their challenge as lonely and uphill. Providers who care for and support individuals with ASD often experience overwhelming feelings of frustration and isolation in the search for appropriate diagnostic and treatment services. The lack of resources available for individuals with ASD, including adequate funding for critical services, appropriate diagnostic tools for very young children, early intervention systems, crisis intervention, continuum of services through the adult years, and professional training

of educators and service providers, leaves a substantial void in the care of individuals with ASD and often prevents them from reaching their full potential as contributing members of society. (Reference: [www.theautismprogram.org](http://www.theautismprogram.org);(10/2008).

## **COMMISSION ON AUTISM SPECTRUM DISORDERS**

House Bill 296 was enacted by the Kentucky General Assembly during its 2005 regular session and signed into law by Governor Ernie Fletcher on March 18, 2005, to establish the Kentucky Commission on Autism Spectrum Disorders. (See the full text of House Bill 296 in [Appendix B](#) to this Report.) The stated purpose of the Commission was to develop a 10 year comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD, and to make recommendations regarding legislation, administrative regulations, and policies to the Governor of Kentucky and the Kentucky General Assembly. [Appendix C](#) to this Report sets forth the members of the Commission and, to the extent applicable, the organization which such individual represented on the Commission.

The Commission was formed in response to the significant increase in the number of Kentuckians diagnosed with ASD over the last 10 to 15 years and to build upon the work of the Autism Spectrum Disorders Advisory Consortium (ASDAC). ASDAC was formed in March, 2002, at the request of the State Interagency Council for Services to Children with an Emotional Disability (SIAC). ASDAC was charged with providing a unified voice to assist SIAC in understanding the needs of children and youth with autism spectrum disorders.

House Bill 296 (2008) mandated that the Commission develop a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD make recommendations regarding legislation, administrative regulations, and policies to the Governor and the General Assembly based on the following:

- Needs for services and supports for individuals who have ASD.
- Funding needs and sources, including state, federal, private, and any other appropriate funding sources.
- Training needs and a plan to implement a comprehensive training system, which shall include the Kentucky Autism Training Center.
- Standards for provider training and qualifications, best practice standards for services, and the need for additional providers.
- Goals for developing health benefit plans that provide insurance coverage for the treatment of ASD.
- A plan for the identification of individuals of all ages with ASD and for the creation of a statewide ASD registry.
- Consistent program and services eligibility criteria.
- The need for coordinated, enhanced, and targeted special education and treatment programs for individuals with ASD.

-Strategies and timelines for establishing an accountable, cost-efficient, and cooperative system of services that integrates and builds upon existing public and private agencies, programs and resources.

-A timeline for implementing and monitoring the recommendations of the plan statewide.

-Based on the above criteria, hours of research and work the Commission developed a set of 15 recommendations in their final report.

-The final report was submitted to Governor Ernie Fletcher, the Kentucky Council on Developmental Disabilities and the Legislative Research Commission on October 1, 2006, as directed by House Bill 296. The Commission was dissolved on October 1, 2007, following the fulfillment of their duties as defined by HB 296.

## **CURRENT STATUS**

(Excerpts taken from Kentucky Long Term Care Profile; Carla Crane, Ph.D. Kedra Fitzpatrick, LCSW, Melissa Hopkins, BS, BBA, Tonia Wells, MSW, CBIS And Kentucky State Profile Tool Implementation Team for the Kentucky Department for Aging and Independent Living; March 2009)

March 2009 Currently, Kentucky lacks the designation of a single public agency or program devoted to serving individuals of any age diagnosed with an Autism Spectrum Disorder (ASD). This lack of designation has resulted in service gaps throughout Kentucky and across the age span for individuals with ASD. Although some children receive services through the public education system under the mandate of the federal IDEA 2004, an adequate service system infrastructure is lacking. As such, other programs, depending upon eligibility guidelines, existence of service providers, and adequacy of funding, are providing various services to individuals with ASD, their families and caregivers. While efforts have been made to develop a comprehensive plan to address the needs of individuals with ASD, funding has not been identified.

## **Programs and Services**

### **HCBS Programs:**

None of Kentucky's existing HCBS programs are specifically designed to comprehensively meet the service demands of individuals with ASD across the lifespan. The following programs or agencies, more fully described in previous sections, may provide some supports: *First Steps*, EPSDT, Head Start, Department of Education, Regional Boards including IMPACT, IMPACT Plus, HART-SL, Michele P., and SCL. However, these programs provide a patchwork of services depending on eligibility criteria including autism as a primary diagnosis versus a co-occurring diagnosis, age, geographic location, and general availability of comprehensive services. Services provided are not evidenced-based nor are professionals specifically trained to provide services to persons with ASD.

By design *First Steps* provides services to infants or toddlers up to age three; therefore, an ASD diagnosis may not be identified in time for a child to receive intensive services. Since the age of onset occurs long after birth, Head Starts and educational systems are more likely to provide initial services to children. Services through the Regional Boards and IMPACT plus may also be utilized during childhood; however, such programs are not designed to provide early intervention, or intensive, long-term care supports. In 1999/2000 Kentucky's Legislative Research Commission's Program and Review Committee evaluated eligibility of children with autism receiving services through IMPACT Plus and many children were determined ineligible against the program criteria. Children and families were then transitioned to the HCB waiver or placed on the waiting list for SCL waiver services as appropriate. Once an individual transitions into adulthood, resources become more limited. Adults are more likely to qualify for long-term care supports if they have co-occurring disabilities that allow them to meet eligibility requirements for programs more specifically designed for other populations.

In 2002 the Autism Spectrum Disorder Consortium was formed at the request of the State Interagency Council for Children's Mental Health (SIAC). The consortium was charged with providing a unified voice to assist SIAC in understanding the needs of children and youth with ASD. As the consortium was forming, the 2002 General Assembly passed HB 455 which required the Cabinet to apply for a federal medical waiver to address the needs of children and youth with ASD in Kentucky. The consortium provided recommendations for an initial framework for a Medicaid waiver; however, the waiver was not approved and efforts to revise the waiver to meet CMS standards were abandoned. Finally, Representative Scott Brinkman proposed legislation that would have established an office for the coordination of funding, services, grants, etc. specific to this population; however, the legislation did not pass. Children, youth, and adults have continued to languish in the state as a result of this disability being "orphaned".

### **Non-HCBS Programs**

Although intensive community based services are lacking in Kentucky, there are several university based initiatives focusing on research, assessment, and/or education. Examples include the Kentucky Autism Training Center (KATC), *Systematic Treatment of Autism and Related Disorders Program (STAR Program)*, Kentucky Assistive Technology Service Network (KATS Network), Eastern Kentucky University Autism & Related Disorders Group, *The Kelly Autism Program (KAP)*, and Autism Services Research Group.

KATC was developed through University of Louisville's College of Education and Human Development in late 1990. The program is funded through a variety of sources and is overseen by the Council for Post Secondary Education. The mission of the Kentucky Autism Training Center is to enhance supports for persons with autism by providing information and technical assistance to families and service providers across Kentucky. KATC offers family assistance, community based services related to supports and training, classroom consultation, school-based team consultations and programs in special education. KATC staff also provide workshops and training seminars on topics of specific interest to families. No direct services are provided.

The *STAR Program* is located within the Weisskopf Child Evaluation Center (WCEC), a division of the University Of Louisville School Of Medicine, Department of Pediatrics. This intervention program has been designed specifically for children with ASD with an emphasis on engagement and learning that can be carried over to home, community, and educational settings.

Components of the family-centered and individualized *STAR Program* include: competency development, assessment and outcomes, and long-term support and follow-up.

*The KATS Network* includes statewide representation of organizations and individuals connecting to enhance the availability of assistive technology devices and services to improve the productivity and quality of life for individuals with disabilities. Individuals who access the network may be provided device demonstration and short-term loans of assistive technology devices, as well as tutorial for using Windows<sup>®</sup> and Macintosh<sup>®</sup> accessibility features. Every school district in Kentucky is a member of a special education cooperative with a staff person dedicated to assistive technology.

*Eastern Kentucky University Autism & Related Disorders Group* is a program through Eastern Kentucky University's (EKU) Department of Psychology, Developmental Disabilities Clinic. Goals of EKU's Autism and Related Disorders Group includes the provision of learning experiences about autism to faculty, staff, and students; dissemination of information, resource for interventions unavailable in the community, and access to parents and parent panels who have children with autism to broaden the knowledge base. EKU's Autism & Related Disorders Group also offers a Teen Social Group that is intended to provide social opportunities and social skill training for teenagers and young adults with autism or other special social needs. Conducted by EKU graduate students in Psychology and other student and community volunteers, this group also provides specialized training opportunities for students.

*The Kelly Autism Program (KAP)* through Western Kentucky University (WKU) was founded in November 2002. KAP focuses on three primary goals: independence, productivity, and community involvement for adolescents and young adults diagnosed along the ASD continuum. KAP works closely with schools and consultants to write and implement an Individualized Education Plan (IEP) designed to meet the student's academic, communication, sensory and social/behavioral goals. KAP is unique regionally and nationally in that it focuses on elementary, middle, high school and post-secondary individuals as well as their families.

*Autism Services Research Group*, a program through University of Kentucky's College of Education, seeks to advance research that improves the quality of life of children with ASD. . Funding for the Autism Services Research Group is provided by the National Institute of Mental Health. Research involves the study of interventions delivered in the community, efficacy of parent-teacher collaboration for students with autism, and other outcomes. The research group adopted the Collaborative Model of Competence and Success (COMPASS) framework to facilitate a collaborative decision-making and understanding of how autism spectrum disorders affects each child individually.

### **Common Non-HCBS Supports and Programs for Individuals with Autism Spectrum Disorder**

- Healthy Start in Child Care: A Kids NOW Initiative to provide consultation on health, safety and nutrition to child care providers;
- Family Resource and Youth Service Centers (FRYSCs): school based centers providing services and referrals for meeting basic needs;
- Highlands Center for Autism: A private day-school for children with ASD;
- Income support from Supplement Security Income (SSI);
- Private Insurance Mandate (Maximum of \$500 per month for covered individuals with ASD whose plans are not self-funded or based out of state);
- University of Kentucky's Human Development Institute Information and Resource Guide; and
- Vocational Rehabilitation.

### **Demographic and Utilization Trends**

Kentucky is experiencing a growing prevalence of autism such that every health care provider and every school can expect to serve children with this type of disorder.

With 1,050,673 people under the age of 18, and the rate of children diagnosed with ASD estimated to be 1 in 150 nationally, Kentucky can expect to identify 7,004 children with ASD per year. According to the Report of Children and Youth with Disabilities Receiving Special Education and Related Services (December 2007), along with other data captured at that time as required under IDEA, 2,367 students (3-21 years old) with autism were identified. Currently, the Autism Society of America estimates that the lifetime cost of caring for a child with autism ranges from \$3.5 million to \$5 million.

Currently, individuals with ASD are under-served and under-represented in the service system. With no specific programs or specially trained provider community, diagnosis of ASD is infrequent. While early intervention is key to persons diagnosed with ASD it can not be accomplished without early screening and diagnosis. Following diagnosis there is no centralized location for parents to access information on resources and services.

Utilization data for existing programs should also be interpreted with caution since other co-occurring diagnosis may be more relevant for eligibility purposes and therefore the only diagnosis collected at intake. In Fiscal Year 2007 Kentucky Vocational Rehabilitation reported serving 248 individuals with autism with the majority, 223, at transition age from youth into adulthood (Age 14-24 at time of application). Table 6 includes comparison data between Fiscal Years 2005 and 2006; as depicted, vocational assessments for individuals with ASD have significantly increased. In Fiscal Year 2007 Kentucky's IMPACT program reported serving 107 children with ASD and 27 adults were provided services through the SCL waiver.

**Table 6. Kentucky Office of Vocational Rehabilitation expenditures by category for individuals with ASD.**

Category	\$ in 2006	% in 2006	\$ in 2005	% in 2005
Assessment	\$106,959.21	46.88%	\$7,762.04	14.95%
Diagnosis and Treatment	\$3,102.39	1.36%	\$2,605.42	5.02%
Training	\$86,262.66	37.80%	\$40,120.22	77.29%
Maintenance	\$682.87	0.30%		
Transportation	\$3,815.64	1.67%	\$192.00	0.37%
Reader/Interpreter/PA Services	\$10,050.00	4.40%		
Computers	\$3,181.90	1.40%	\$529.84	1%
Other	\$14,102.39	6.18%	\$697.86	1.34%
	\$228,157.06		\$51,907.38	

## **Components Associated with Balancing**

### ***Consolidated State Agency and Single Access Points***

Individuals with ASD represent a heterogeneous group of individuals with diverse and wide-ranging treatment needs. To date, Kentucky does not have a consolidated or single agency responsible for such diverse needs. As such, individuals may enter various systems as there is no single access point for services.

### ***Facility Supply Controls and Transitions from Facilities***

Previous sections describe supply controls for various facility settings of which some individuals with ASD may qualify. There are no designated facilities to serve individuals with ASD nor is there a concerted effort to specifically identify individuals in such settings who could potentially be transitioned to the community.

### ***Continuum of Residential Options***

Families provide the primary supports in order for children with ASD to remain living in their homes and communities. The continuum of residential services presented in previous chapters may also be an option for some individuals with ASD depending upon their level of care needs and respective eligibility criteria of each residential setting. Residential settings specifically for individuals with autism have not been created or identified in the current system.

### ***HCBS Infrastructure Development***

Enacted by the Kentucky General Assembly during its 2005 regular session and signed into law on March 18, 2005, House Bill 296 established the Kentucky Commission on Autism Spectrum Disorders (The Commission on ASD). The stated purpose of the Commission was to develop a ten-year comprehensive state plan for an integrated system of training, treatments, and services

for individuals of all ages with ASD, and to make recommendations regarding legislation, administrative regulations, and policies to the Governor of Kentucky and the Kentucky General Assembly.

The Commission was formed in response to the significant increase in the number of Kentuckians diagnosed with ASD over the last 10 to 15 years and to build upon the past work of the Autism Spectrum Disorders Advisory Consortium (ASDAC). The Commission on ASD developed a set of 15 recommendations in their final report. The final report was submitted to the Governor's Office, the Kentucky Council on Developmental Disabilities, and the Legislative Research Commission, on October 1, 2006 and the Commission on ASD was dissolved on October 1, 2007. A copy of the report can be found at <http://chfs.ky.gov/NR/rdonlyres/409D047E-FC53-4943-9CF3-CE89FF1B7DC5/0/final.DOC>. Funding for recommended changes and implementation has not been identified.

### ***Participant Direction and Quality Management***

Currently, there are no programs specifically developed to serve individuals with ASD; therefore, the opportunity to integrate participant direction and quality management strategies has not occurred.

### **Summary**

ASD services are delivered through a patchwork of programs and providers without adequately meeting the comprehensive and complex needs of individuals with ASD across the lifespan. While various universities have developed strategies to support individuals with ASD and their families, there is no consolidated state agency or single access point for consumers to gain services. Enacted by legislation, the Commission on ASD has provided recommendations to meet the growing service demands of individuals with ASD. The Commission on ASD was dissolved in 2007 and a comprehensive service system for individuals with ASD is still needed.

## **ANNUAL UPDATE**

The Kentucky Council on Developmental Disabilities (KCDD) has the responsibility under House Bill 296 to monitor the implementation of the state plan, where appropriate, make recommendations on the need for modifications to the state plan and to submit an annual report to the Governor by October 1<sup>st</sup> of each year beginning in 2007 and continuing until 2016.

The following sets forth the annual update on the recommendations of the Commission regarding the legislation, administrative regulations and policies necessary to develop and implement a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with ASD.

During the 2009 legislative session Rep. Scott Brinkman entered HB 190 for consideration

HB 190/HM (BR 431) - S. Brinkman, L. Clark, R. Crimm, T. Edmonds, C. Embry Jr., K. Hall, D. Osborne, K. Sinnette, A. Webb-Edgington, S. Westrom

AN ACT relating to health insurance.

Create new sections of Subtitle 17A of KRS Chapter 304 to define terms "applied behavior analysis," "autism services provider," "autism spectrum disorders," "diagnosis of autism spectrum disorders," "habilitative or rehabilitative care," "health insurance policy," "medically necessary," "pharmacy care," "psychiatric care," "psychological care," "therapeutic care," and "treatment for autism spectrum disorders"; require health policies covered in this subtitle to provide coverage for the diagnosis and treatment of autism spectrum disorders and their related conditions; prohibit insurance policies from limiting the number of visits an insured may make for such services; allow services provided by this section to be subject to copayment, deductible, and coinsurance provisions; give insurers the right to request a review of treatment, provided for by this section, not more than once every 12 months unless the insured's physician or psychologist agrees that a more frequent review is necessary; amend KRS 18A.225 to require policies provided to state employees to cover the diagnosis and treatment of autism spectrum disorders.

#### HB 190 - AMENDMENTS

HFA (1, J. Greer) - Delete original provisions of the bill and substitute a provision that the Legislative Research Commission direct the Interim Joint Committee on Banking and Insurance to conduct a study of health insurance coverage of autism spectrum disorder.

Feb 3-introduced in House

Feb 4-to Banking & Insurance (H)

Mar 2-floor amendment (1) filed

Mar 3-posting waived

<http://www.lrc.ky.gov/record/08RS/HB188.htm> 7/09

The original bill was amended to direct the Joint Committee on Banking and Insurance to conduct a study on insurance coverage for autism spectrum disorders. The bill passed out of the House but was not introduced in the Senate.

Beginning in 2008 several bills have been introduced in the House however none have passed into law. The bills range from creating an Office on Autism to supporting insurance coverage for individuals with Autism. While several states in the nation are aggressively addressing the needs of persons with Autism from a legislative perspective, Kentucky has not.

In August of 2008 Kentucky was selected by the National Professional Development Center on Autism Spectrum Disorders to be one of only three states to receive technical assistance related to autism, which affects more than 2,300 school-aged children statewide. Of nine partnership applications nationwide, Kentucky, Michigan and Minnesota were selected to receive the assistance.

The Kentucky Department of Education (KDE) and the Kentucky Autism Training Center (KATC), located at the University of Louisville, partnered on the application. KDE and KATC will work in collaboration with the FPG Child Development Institute at the University of North Carolina at Chapel Hill, the Waisman Center at the University of Wisconsin-Madison and the M.I.N.D. Institute at the University of California Davis Medical School to implement the two-year project. KDE and KATC also will partner with the statewide network of Special Education Cooperatives and Early Childhood Regional Training Centers, Kentucky's Infant-Toddler Program (First Steps), the Parent Training and

Information Network (KY-SPIN), the Kentucky Council on Developmental Disabilities, institutions of higher education and many other state partners.

The National Professional Development Center on Autism Spectrum Disorders will provide professional development and technical assistance to help Kentucky promote implementation of evidence-based practices for early identification, intervention and education for children and youth with Autism Spectrum Disorders (ASD). These practices should produce the best possible outcomes for families and students with ASD, spanning the age range from infancy to early adulthood (21 years). In addition, the center will help Kentucky establish model sites demonstrating evidence-based practices for ASD and in evaluating and measuring child, family, practitioner and system-level outcomes.

The purposes of the two-year project, which will begin in Kentucky in January 2009, are to:

- ☐ increase the number of highly qualified personnel (particularly teachers and practitioners) serving children and youth with ASD in Kentucky
- ☐ establish a sustainable system of professional development in evidence-based practices in ASD
- ☐ provide technical assistance support for early childhood practitioners, educational leaders, teachers and school-based personnel

Through this partnership some of the recommendation of the Autism Commission has been addressed.

#### RECOMMENDATION NUMBER 1

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation creating a “Supports for Individuals with Autism Spectrum Disorders Program” (the Program) within the Cabinet for Health and Family Services. The Program would be responsible for implementing and monitoring services and supports for individuals with ASD and their families and caregivers. In support of the Program, the General Assembly should enact biennium budgets that provide targeted funding for the services and supports for individuals with ASD, their families and caregivers, receiving services through the Program using both state general fund revenues as well as funds available under the Medicaid program. The Program would be staffed with qualified personnel assigned exclusively to the Program. The administrative costs of staffing and operating the Program would also be financed with a combination of state general fund revenues as well as Medicaid funds. The Program would serve as a state-centric office and coordinating body to keep an active inventory of services and resources available to individuals with ASD, their families and caregivers that would be posted on a user-friendly website and promoted to individuals with ASD, their families and caregivers, educators, health care providers and other service providers. The Program would establish clear guidelines and criteria for service providers to participate in the Program, and the Program would contract with these service providers throughout Kentucky to deliver approved services to individuals with ASD covered under the Program. The Program should incorporate, to the fullest extent permitted under the Medicaid program, provisions authorizing self-determination and establishing a consumer directed option, whereby individuals with ASD, their families and caregivers would have wide discretion in determining the services best-suited to meet the needs of the individual with ASD and the service providers best-situated to deliver those services. The implementation of this Recommendation is critical to the implementation of many of the Recommendations set forth later in this Report

This recommendation was not addressed in 2009

#### RECOMMENDATION NUMBER 2

The legislation creating the Program should include the creation of an advisory board consisting of family members, including parents and siblings, as well as legal guardians, of individuals with ASD, service providers, adults with ASD and other interested citizens that would consult regularly with the executive management personnel of the Program regarding the functions, duties and mission of the Program. The advisory board should be appointed and functioning contemporaneously with the creation of the Program to help ensure citizen involvement from the outset in helping to implement and maintain the Program. The administrative budget for the Program should include appropriate

financial support for members of the advisory board, including reimbursement of approved travel expenses and perhaps a per diem stipend and reimbursement of reasonable child care or respite care expenses, to ensure that all members of the advisory board can afford to attend its meetings. The advisory board would serve as a conduit between the public and the Program in order to provide structured input to the Program regarding the quality and quantity of the services being provided through the Program as well as all other aspects of the Program.

This recommendation was not addressed in 2009

### RECOMMENDATION NUMBER 3

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation directing the Department of Medicaid Services (DMS) of the Cabinet for Health and Family Services to submit an application to the Center for Medicare and Medicaid Services (CMS) of the federal Department of Health and Human Services for a waiver (the Waiver) that will authorize DMS to develop and implement flexible reimbursement and payment strategies that reflect the individually determined needs for services and supports by individuals with ASD receiving services through the Program. The Waiver should be submitted under the provisions of federal law that will grant DMS the greatest latitude in structuring payment provisions for individuals receiving services through the Program and reimbursement provisions for service providers participating in the Program. The Cabinet for Health and Family Services, in collaboration with the Kentucky Council on Developmental Disabilities, should have the primary responsibility to draft and submit the Waiver including making the determination of whether to pursue the Waiver as a demonstration waiver under Section 1115 of the federal Social Security Act, as a Home and Community Based Services (HCBS) waiver under Section 1915(c) of the federal Social Security Act, as a combined waiver under Sections 1915(b) and Section 1915(c) of the federal Social Security Act, as a combined waiver under Section 1915 of the federal Social Security Act and the Deficit Reduction Act of 2005, as a separate waiver under the Deficit Reduction Act of 2005, or under other provisions of federal law. In determining the most appropriate legal basis for the Waiver, the Cabinet for Health and Family Services and the Kentucky Council on Developmental Disabilities should select the course of action that will assure the greatest likelihood of success in implementing this Recommendation. The Waiver should be written broadly to accommodate the use of a number of revenue streams, including state general fund revenues as well as funds available under the Medicaid program, in order to provide adequate reimbursement to providers of services to individuals with ASD, their families and caregivers. The Commission strongly recommends that the legislation authorizing and directing the preparation and submission of the Waiver ensure that individuals with ASD have the option to continue to receive services under, or to first seek to receive services under, any other waiver program approved by CMS or under the authority of the Deficit Reduction Act or other provisions of federal and state law, and who otherwise meet the applicable eligibility guidelines, instead of receiving services through the Program. The Commission recognizes the importance of ensuring that individuals with ASD and their families and caregivers retain the option to seek or to otherwise continue to receive services under different waiver programs or under other provisions of federal and state law.

This recommendation was not addressed in 2009

### RECOMMENDATION NUMBER 4

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation that will appropriate state general funds in each biennium budget that provide targeted funding for the services and supports needed by individuals with ASD who do not meet the eligibility guidelines for Medicaid waiver services. This Recommendation is supplementary to Recommendation Number 3.

This recommendation was not addressed in 2009

#### RECOMMENDATION NUMBER 5

The executive and legislative branches of state government should continue indefinitely full funding of the First Steps program based upon the number of children participating in the program and the actual costs of providing services to these children, which should include additional funding to the extent necessary to ensure that all children with ASD participating in the First Steps program receive all needed services for effective early intervention.

This recommendation was not addressed in 2009

#### RECOMMENDATION NUMBER 6

The Program should enter into an interagency agreement with the Kentucky Department of Education to ensure a coordinated and effective system of delivery of services to children with ASD who are enrolled in the public school system. The Program and the Kentucky Department of Education should maximize the services received by a student with ASD through both the Program and under the federal Individuals with Disabilities Education Improvement Act (IDEIA). The elements of the interagency agreement should include, at a minimum, the following components:

The requirement that the Kentucky Department of Education expand its current classification eligibility criteria for autism to be consistent with the DSM-IV-TR for Pervasive Developmental Disorders. An expanded definition that matches the DSM-IV-TR will allow children with Pervasive Developmental Disorders Not Otherwise Specified and Asperger's Disorder (as well as the less commonly identified Rett's Disorder and Childhood Disintegrative Disorder) to receive educational services under the educational classification of autism.

The requirement that, as part of the Program's statutory duties, mission and budget, qualified staff of the Program will serve as advocates for children with ASD to ensure that these children receive through the public school system all services that are guaranteed to them under IDEIA, together with the requirement that the Program provide trained personnel to assist parents and guardians in negotiating Individual Education Plans (IEPs) for these children that will include the provision of all guaranteed services under IDEIA.

The inclusion of provisions guaranteeing that all children with ASD qualify for extended school day services and extended school year services without the need to show regression in the absence of participation in the programs. The Commission believes that the Kentucky General Assembly has adequately funded for the current biennium the extended school day and extended school year services programs.

The requirement that the Kentucky Department of Education hire more complex needs consultants to ensure adequate staffing within each special needs cooperative within the Commonwealth of Kentucky.

The requirement that the Kentucky Department of Education inform parents or legal guardians of children with ASD enrolled in the public school system of the desirability of the referral of the child for a medical evaluation prior to graduation to help facilitate the child accessing federal and state benefits that, depending upon the eligibility guidelines of the particular program, may be available to the child when he or she reaches the age of 21.

Require the program to enter into an interagency agreement with the Kentucky Department of Education for the effective delivery of services to children with ASD.

This recommendation partially addressed by the National Professional Development Center on Autism Spectrum Disorders grant received by the Department of Education.

## RECOMMENDATION NUMBER 7

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation that mandates specific screening for ASD of all children at each of the 18 month well-baby check, the 2-year old well-child check, the 4-year old well-child check, the initial school physical, and the 6<sup>th</sup> grade school physical. ASD specific screening should also occur at all initial visits to the First Steps program of children 18 months and older and other early intervention programs should also be encouraged to perform ASD specific screenings.

All ASD specific screenings should utilize the most current, evidence-based screening tools as endorsed by the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry and the American Academy of Neurology. These screening tools currently include, at a minimum, the MCHAT (Modified Checklist for Autism in Toddlers) for children from 18 months to 24 months of age, the Social Communication Questionnaire (Berument, Rutter, Lord, Pickles & Bailey, 1999) for the wellness check at age 4 and the school physical at age 6, and the Autism Spectrum Screening Questionnaire (Ehlers, Gilberg & Wing 1999) for children from 6 through 17 years of age. The Program should also have the statutory authority and qualified staff to investigate other screening tools and programs employed in other states to determine and report to health care providers, educators and other professionals the effectiveness of these other screening tools and programs based upon data and findings that the Program deems reliable. An example of the type of program that may merit investigation by the Program is the First Signs® program (not to be confused with Kentucky's First Steps program), which has been implemented in a number of states.

If ASD is suspected following a screening, a formal diagnosis should be made within 90 calendar days after the initial screening. The formal diagnosis should be made by qualified professionals in good standing who have the right and ability to diagnose ASD within their lawful scope of practice as authorized under KRS Chapters 311, 314, 319, or 335 and administrative regulations promulgated by the professional's board or council of licensure.

This recommendation not addressed in 2009.

## RECOMMENDATION NUMBER 8

The Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation modeled after the legislation enacted in Indiana in 2001 mandating insurance coverage for individuals with pervasive developmental disorder that is far more expansive than the autism benefit mandated in KRS 304.17A-143 (i.e., a monthly benefit of \$500 for certain services for individuals with autism). The Indiana legislation, a copy of which is included as Appendix M to this Report, should however be modified by the Kentucky General Assembly in several respects as noted below.

The Indiana legislation defines pervasive developmental disorder as a neurological disorder and not as a mental health or emotional disorder, and thus precludes insurance companies from denying or restricting coverage for services to covered individuals with pervasive developmental disorder on the basis that the condition is a mental and not a medical condition. The legislation also mandates insurance coverage for all services prescribed by the attending physician under a treatment plan formulated for the individual with pervasive developmental disorder. Self-insured plans are, however, exempt from the mandate. Although the Indiana legislation does not include a statutory dollar limitation on the required insurance coverage for pervasive development disorder comparable to Kentucky's current \$500 per month limitation on the mandated coverage for services to children with autism, the Indiana legislation does permit the insurer to impose dollar limits, deductibles, and coinsurance provisions with respect to the mandated insurance coverage for pervasive development disorder provided that such dollar limits, deductibles, and coinsurance provisions are no less favorable to the insured than the dollar limits, deductibles, and coinsurance provisions that are imposed with respect to physical illness covered under the insurance policies regulated by the legislation.

The Kentucky General Assembly and the Governor of Kentucky should modify and improve the Indiana legislation in three respects. First, Kentucky's version of the legislation should explicitly provide coverage for all

disorders within ASD as defined in the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association, fourth edition (DSM-IV). The Indiana legislation covers individuals with pervasive developmental disorder, which may not be as broad as autism spectrum disorders. Second, Kentucky's version of the legislation should explicitly eliminate the need for a dual diagnosis of an insured with ASD and instead provide coverage to an insured diagnosed with ASD regardless of whether Kentucky law, the insurance industry, the particular insurer or experts in the field of ASD considers ASD a neurological disorder, a medical condition or a mental health or emotional disorder. Indiana's legislation explicitly defines pervasive developmental disorder as a neurological condition, which can result in certain services being denied coverage on the basis that such services treat a mental condition as opposed to a medical condition. Third, Kentucky's version of the legislation should not impose any dollar limitation on the mandated insurance benefit but instead require coverage for all services prescribed by the attending physician under a treatment plan formulated for the individual with ASD. Indiana's legislation permits an insurer to impose a dollar limit on the insurance coverage equal to any dollar limit imposed with respect to physical illness covered under the insurance policy. The Commission believes that the treatment plan formulated by the insured's attending physician should be the basis for determining the scope of coverage provided under the insurance policy and not an artificial dollar limitation that may result in the insured receiving inadequate coverage for necessary services under the insurance policy.

This recommendation was not addressed although legislation us introduced for consideration HB 190 would have prohibited insurance policies from limiting the number of visits an insured may make for such services; allow services provided by this section to be subject to co-payment, deductible, and coinsurance provisions; give insurers the right to request a review of treatment, provided for by this section, not more than once every 12 months unless the insured's physician or psychologist agrees that a more frequent review is necessary; amend KRS 18A.225 to require policies provided to state employees to cover the diagnosis and treatment of autism spectrum disorders.

#### Recommendation Number 9

The Commission recognizes that Recommendation Number 8 is ambitious. Although the Commission encourages Kentucky's policy makers to be bold in addressing the need to improve insurance coverage for individuals diagnosed with ASD, the Commission equally recognizes the political difficulties in enacting a broad insurance mandate for services to individuals with ASD during a time of increasing health care costs and health insurance premiums. Accordingly, if Kentucky's legislators and executive branch are not prepared to enact legislation modeled after the Indiana legislation described in Recommendation Number 8, with the modifications noted in Recommendation Number 8, the Commission makes the following recommendations, which should serve as interim measures until such time as the Kentucky General Assembly and the Governor of Kentucky are prepared to fully implement Recommendation Number 8. Specifically, the Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation amending KRS 304.17A-143 to expand the mandated benefit of \$500 per month for children covered under a health benefit plan to all children diagnosed with any condition identified under ASD. Currently, KRS 304.17A-143 limits the insurance benefit to children diagnosed with autism. In addition, the Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation amending KRS 304.17A-143 and 806 KAR 17:460 to eliminate the imposition of any deductibles, coinsurance, and co-payments to this benefit, as well as to provide that the \$500 per month benefit shall increase annually by a percentage equal to the percentage increase in the Cost of Living Index for the prior year. The Kentucky Office of Insurance should also amend the definition of therapeutic or rehabilitative care set forth in 806 KAR 17:460(5) to include within this definition both Applied Behavior Analysis (ABA) therapy as well as other evidenced-based therapies that have been widely documented to improve the verbal, learning, social and other skills of children with ASD. The \$500 per month benefit for therapeutic, respite and rehabilitative services for a child with ASD should be on a "first dollar" basis, thereby ensuring that the full benefit is available for children with ASD covered under a health benefit plan, and the monthly benefit should keep pace with the rate of inflation. The Commission also recommends that the Kentucky General Assembly should enact, and the Governor of Kentucky should sign into law, legislation amending KRS 304.17-310 to specifically include ASD with mental retardation and physical disability as a condition which will not preclude a child

from continuing to be covered under a family health insurance policy. KRS 304.17-310 currently mandates the continuation of coverage for children under the family health insurance policy, regardless of age, who are incapable of self-sustaining employment by reason of mental retardation or physical disability. Finally, advocacy groups involved in ASD should be encouraged to aggressively inform all parents and caregivers of children with any condition identified under ASD of the existence of this statutory mandate for all fully insured health benefit plans issued or renewed in Kentucky.

The recommendations set forth in this Recommendation Number 9, if implemented, would clearly improve insurance coverage for insureds diagnosed with ASD but, in the opinion of the Commission, would not be as effective as Recommendation Number 8 in assisting insureds diagnosed with ASD to access critical services.

This recommendation not addressed although legislation us introduced for consideration HB 190 would have prohibited insurance policies from limiting the number of visits an insured may make for such services; allow services provided by this section to be subject to co-payment, deductible, and coinsurance provisions; give insurers the right to request a review of treatment, provided for by this section, not more than once every 12 months unless the insured's physician or psychologist agrees that a more frequent review is necessary; amend KRS 18A.225 to require policies provided to state employees to cover the diagnosis and treatment of autism spectrum disorders.

#### RECOMMENDATION NUMBER 10

The Commission carefully considered the formulation of a plan for the identification of individuals of all ages with ASD and the creation of a statewide ASD registry. The Commission believes that, based upon comments received at public hearings held to consider the preliminary draft of this Report as well as at meetings of the full Commission, there currently exists strong opposition by parents of children with ASD to the creation of a statewide ASD registry. The Commission does not therefore believe that the creation of a statewide ASD registry at this juncture is politically feasible. The Commission does however recognize that, if the Program is created, the Program will gather information regarding individuals in Kentucky with ASD who receive services through the Program. Although the Program will be required under existing law to maintain the confidentiality of such information, the Program will be able to identify those individuals with ASD residing in Kentucky who are receiving services through the Program. Accordingly, the more success the Program achieves in facilitating the delivery of services to Kentuckians with ASD, the more certainty will exist in the determination of the actual number of Kentuckians of all ages with ASD.

This recommendation was not addressed

#### RECOMMENDATION NUMBER 11

Advocacy groups involved in ASD should consider formally requesting Kentucky's federal congressional delegation to introduce legislation amending the federal Employee Retirement Income Security Act (ERISA) to incorporate a mandate for covered insureds diagnosed with ASD comparable to the mandate set forth in KRS 304.17A-143 (as amended in accordance with Recommendation Number 8) with respect to all self-funded health insurance plans governed under ERISA. These advocacy groups should also consider formally requesting government employers with self-funded plans to include a comparable benefit in their health insurance plans for covered insureds diagnosed with ASD.

This recommendation was not addressed however there are activities at the national level on Autism.

#### RECOMMENDATION NUMBER 12

The stated mission of the Program should include the development of a comprehensive training plan for the systematic training of professionals and paraprofessionals to deliver necessary services to individuals with ASD, their families and caregivers. Consistent with House Bill 296, the Program should utilize the Kentucky Autism Training Center to implement the comprehensive training plan pursuant to a written contract that clearly sets forth the duties and

obligations of the Kentucky Autism Training Center and the goals and objectives of the Program, and that creates appropriate oversight of, and requires accountability from, the Kentucky Autism Training Center. In turn, the Kentucky Autism Training Center, consistent with its statutory duties, should maintain extension partnerships at the public universities in Kentucky to create a statewide model for delivery of training to pre-service and service providers and evaluators in their respective regions that will incorporate best practices, which is defined by the Kentucky Department of Mental Health and Mental Retardation (DMHMR) as a continuum of practices and programs ranging from promising to evidence-based to science-based. University partners will be expected to provide an approved plan for training pre-service and service providers and evaluators in their region as well as a plan for tracking and monitoring the quantitative and qualitative effectiveness of services delivered to individuals with ASD, their families and caregivers in their region in order to receive and maintain grants approved through the Program. A more detailed description of this recommendation is set forth in Appendix N to this Report. The public universities should also be encouraged to develop associate, baccalaureate and graduate service and training programs and research opportunities that are staffed by both faculty and students. The Commission recommends that the Kentucky General Assembly increase the annual funding provided to the Kentucky Autism Training Center to a level sufficient to enable it to perform its traditional training functions as well as the training functions envisioned in this Recommendation. Private universities and colleges that choose to train pre-service and service providers and evaluators as part of their academic and public service missions should not be precluded from also establishing extension partnerships with the Kentucky Autism Training Center.

The Program should also enter into memoranda of agreements with other regional centers that may include, without limitation, education cooperatives, regional early childhood training centers and community mental health centers, in order to coordinate the education and training of educators, health care providers and other service providers who interact on a professional basis with individuals with ASD as well as to coordinate the education and training of families and caregivers of individuals with ASD. The Program should utilize these regional centers to develop statewide training activities that are coordinated and collaborative, are sensitive to and based on local needs, are individualized for specific type of service provider, and are continuously monitored for outcomes. In developing statewide training activities, the regional centers should incorporate the following:

The conduct of periodic surveys of educators, health care providers, other service providers and individuals with ASD, their families, and caregivers to assess the quantitative and qualitative aspects of services provided.

The utilization of the results of the periodic surveys to determine the fiscal and programmatic needs of educators, health care providers, other service providers, and individuals with ASD, their families, and caregivers, and the dissemination of such results and determinations to Kentucky's policy makers including the Office of the Governor and the General Assembly.

The periodic assessment of efforts in other states in providing services to individuals with ASD, their families and caregivers, and the formulation of recommendations to policy makers, educators, health care providers, other service providers, families and caregivers, where appropriate, regarding the implementation of successful practices in other states.

The provision of research opportunities to assess the quality and effectiveness of services, the provision of best practices' training, and the provision of supportive care for parents and caregivers through continued public funding and the development of private source funding streams.

As part of the comprehensive training plan, the Program should identify regional centers that are willing to review, assemble, formulate, update and disseminate information regarding best practices for treating individuals with ASD to educators, health care providers, other service providers, families and caregivers in their region, and the Program should enter into memorandum of agreements with these regional centers to provide training on a regular basis to these individuals that incorporate best practices for treating individuals with ASD. In developing statewide training activities, the regional centers should incorporate the following:

The application of best practices to training techniques that includes direct observation, feedback and coaching, follow-up, and access to ASD consultants.

The development of local training of trainers including through direct interactions with individuals with ASD, structured problem solving, and coordinated planning and implementation of strategies.

The establishment of accountability in publicly funded service systems, the creation of incentives for training service providers, and the development of the systematic compilation and reporting of outcomes.

The development of effective systems to timely disseminate current information regarding best practices to educators, health care providers, other service providers, and families and caregivers.

The development of a systematic approach to the incorporation of best practices in public and private school systems and with providers of services to individuals with ASD. The Program should have the statutory authority to contract with entities in the private sector, including non-profit organizations, to assist in the training of educators, health care providers and other service providers as well as the education and training of families and caregivers of individuals with ASD.

Require the program to develop a comprehensive training plan and contract with the Kentucky Autism Training Center to implement the plan.

2008 – HB 188 was amended in House; removed stipulation.

**This recommendation partially addressed by the** National Professional Development Center on Autism Spectrum Disorders grant received by the Department of Education.

Kentucky has been selected by the National Professional Development Center on Autism Spectrum Disorders to be one of only three states to receive technical assistance related to autism, which affects more than 2,300 school-aged children statewide.

The Kentucky Department of Education (KDE) and the Kentucky Autism Training Center (KATC), located at the University of Louisville, partnered on the grant application. KDE and KATC will work in collaboration with the FPG Child Development Institute at the University of North Carolina at Chapel Hill, the Waisman Center at the University of Wisconsin-Madison and the M.I.N.D. Institute at the University of California Davis Medical School to implement the two-year project. KDE and KATC also will partner with the statewide network of Special Education Cooperatives and Early Childhood Regional Training Centers, Kentucky's Infant-Toddler Program (First Steps), the Parent Training and Information Network (KY-SPIN), the Kentucky Council on Developmental Disabilities, institutions of higher education and many other state partners.

The purposes are to:

- increase the number of highly qualified personnel (particularly teachers and practitioners) serving children and youth with ASD in Kentucky
- establish a sustainable system of professional development in evidence-based practices in ASD
- provide technical assistance support for early childhood practitioners, educational leaders, teachers and school-based personnel

Additional funds were not awarded at the state or federal level

### RECOMMENDATION NUMBER 13

The Program should promote the creation of a comprehensive resource network, including interagency transition teams within agencies responsible for providing services to individuals with ASD, to help facilitate successful transitions for individuals with ASD from childhood to adulthood. The Program should pursue the following strategies in developing the resource network:

Seek Program representation on the Kentucky Interagency Transition Council for Persons with Disabilities.

Seek Program representation on regional Interagency Transition Teams.

Enter into memorandum of agreements with the state agencies responsible for administering programs and services for adults with disabilities such as vocational rehabilitation, supported living and supported employment to help assist individuals with ASD in making the transition from childhood to adulthood including transitioning from the public school system or private school to employment within a workplace environment appropriately structured to enable the adult with ASD to perform a job that matches the demands of the position with the skills and capabilities of the individual.

Assist the Office of Vocational Rehabilitation in expanding services for individuals with ASD to address their diverse range of needs, limitations and challenges. The expansion of services for individuals with ASD should focus particularly on social skills training, including strategies to develop communication skills, as well as support to address restrictive, repetitive and/or stereotyped patterns of behavior that might otherwise preclude these individuals from securing employment. Assistance should also be provided to the Office of Vocational Rehabilitation in obtaining increased supported employment funding from the Kentucky General Assembly to adequately provide these services.

Provide general and ASD-specific training to participating state agencies that targets both the development and the implementation of comprehensive transition plans for individuals with ASD.

Identify and make available to participating agencies and appropriate service providers resources such as books, videos and other appropriate information to address ASD- specific issues for instruction and generalization of skills across settings.

Incorporate both person-centered and practical strategies into individual plans, such as Individualized Transition Plans (ITPs) and Individualized Plans for Employment (IPEs), as a means to create better outcomes in transition.

Encourage the teaching of self-determination skills as a component of the transition process.

Develop, disseminate and maintain a current reference guide that provides a description of agencies and services provided to individuals with ASD.

Identify schools and agencies that are demonstrating exemplary implementation of transition strategies and activities with positive outcomes for students. Provide incentives for these successful programs to become “model” or “demonstration” sites for other schools and agencies.

Develop requests for proposals for schools and other adult service agencies to develop state-of-the-art programs for transition from childhood to adulthood based on the latest evidence-based practices and

innovative ideas. The Program should also have the statutory authority and qualified staff to collaborate with the Office of Vocational Rehabilitation to investigate programs in other states that encourage employers to train, support and hire individuals with ASD. Based on reliable data and findings regarding the effectiveness of these programs in accomplishing their stated mission, the Program's staff should have the authority to make recommendations to policy makers and the public regarding the establishment of comparable programs in the Commonwealth of Kentucky.

THIS RECOMMENDATION PARTIALLY ADDRESSED BY THE NATIONAL PROFESSIONAL DEVELOPMENT CENTER ON AUTISM SPECTRUM DISORDERS GRANT RECEIVED BY THE DEPARTMENT OF EDUCATION.

#### RECOMMENDATION NUMBER 14

The Legislative Research Commission should establish a permanent subcommittee of the Interim Joint Committee on Health and Welfare of the Kentucky General Assembly to focus on issues pertaining to ASD during each annual interim period of the General Assembly. The focus of the subcommittee should be to review any administrative regulations adopted that pertain to the Program or its duties and obligations, as well as other issues involving ASD. The subcommittee should also be responsible for reviewing and discussing any proposed legislation necessary to effectuate the recommendations of the Kentucky Commission on Autism Spectrum Disorders or to otherwise enhance the quality of life for individuals with ASD, their families and caregivers. These issues may include issues pertaining to the education of individuals with ASD, the health care needs of individuals with ASD, and the services and supports needed by individuals with ASD in order to lead lives with dignity and opportunity.

The recommendation was no addressed.

#### RECOMMENDATION NUMBER 15

The Kentucky Department of Education should prepare an updated version of the statewide Technical Assistance Manual on Autism for Kentucky Schools that was published in 1997 in order to incorporate more recent data, best practices, strategies and other relevant information developed since 1997 in order to assist school districts and educators to more effectively educate children with ASD. The Department of Education should encourage all school districts within the Commonwealth to fully utilize the Manual in order to ensure that all teachers of children with ASD as well as other school personnel who interact on a professional level with these children are fully informed of the unique challenges associated with the education of children with ASD and the proven strategies known to enhance the learning experience of the child. The Kentucky Department of Education should be proactive in seeking input from parents, guardians, caregivers and other concerned citizens as part of the process of updating the Manual. Finally, the Kentucky Department of Education should adopt a policy of updating the Manual on a periodic basis to ensure the effectiveness and relevancy of the Manual in assisting all Kentucky school districts to provide, to the greatest extent possible, a meaningful and outcome-driven educational experience for children with ASD.

. 2008 – HB 188 was amended in House; removed stipulation.

This recommendation partially addressed by the National Professional Development Center on Autism Spectrum Disorders grant received by the Department of Education. Kentucky has been selected by the National Professional Development Center on Autism Spectrum Disorders to be one of only three states to receive technical assistance related to autism, which affects more than 2,300 school-aged children statewide.

The Kentucky Department of Education (KDE) and the Kentucky Autism Training Center (KATC), located at the University of Louisville, partnered on the grant application. KDE and KATC will work in collaboration with the FPG Child Development Institute at the University of North Carolina at Chapel Hill, the Waisman Center at the University of Wisconsin-Madison and the M.I.N.D. Institute at the University of California Davis Medical School to implement the two-year project. KDE and KATC also will partner with the statewide

network of Special Education Cooperatives and Early Childhood Regional Training Centers, Kentucky's Infant-Toddler Program (First Steps), the Parent Training and Information Network (KY-SPIN), the Kentucky Council on Developmental Disabilities, institutions of higher education and many other state partners.

The purposes are to:

- increase the number of highly qualified personnel (particularly teachers and practitioners) serving children and youth with ASD in Kentucky
- establish a sustainable system of professional development in evidence-based practices in ASD
- provide technical assistance support for early childhood practitioners, educational leaders, teachers and school-based personnel

Additional funds were not awarded at the state or federal level

### **TIMELINE FOR IMPLEMENTING AND MONITORING THE RECOMMENDATIONS OF THE PLAN STATEWIDE**

Legislation to implement the recommendations of the Commission was drafted and reviewed by all necessary stakeholders prior to the commencement of the 2007 regular session of the Kentucky General Assembly, and the legislation should be introduced during the 2007 regular session and each subsequent session of the General Assembly until all legislation necessary to implement the recommendations of the Commission has been enacted into law. The Commission affirmative recognizes that the sustained, focused and continuing education of public officials and other policy makers regarding the needs of individuals with ASD, their families and caregivers will be critical to the implementation of the recommendations set forth in this Report as well the adoption of other public policy initiatives intended to address the growing challenges to society presented by ASD. Effective advocacy by groups and individuals involved with ASD will be critical to the successful implementation of the recommendations of the Commission. These groups and individuals should collaborate to the greatest extent possible in order to avoid factionalism and conflict that may cause confusion among legislators and other policy makers when considering policy initiatives designed to improve the services and supports for individuals with ASD and their families and caregivers. A focused advocacy effort within a single umbrella organization could help facilitate the obtaining of grants, private funding and donations in order to effectively advocate for the enactment of legislation, change in administrative policies, and other matters of concern to individuals with ASD and their families and caregivers.

If enabling legislation necessary to implement the recommendations of the Commission is timely enacted into law, Kentucky should establish as a goal the complete implementation of all of the recommendations of the Commission, including the provision of adequate funding for the implementation of all of the recommendations, by the year 2016.

### **DRAFT LEGISLATION FOR IMPLEMENTING THE COMPREHENSIVE STATE PLAN DEVELOPED BY THE COMMISSION**

The implementation of many of the recommendations of the Commission set forth in the Report will require the enactment of legislation in the Commonwealth of Kentucky. The Commission believes that most, if not all, of those recommendations requiring statutory changes to Kentucky law will be embodied in proposed legislation that will be filed in advance of the 2007 regular session of the Kentucky General Assembly. The Commission encourages individuals with ASD, their families and caregivers, service providers and other interested citizens to monitor such legislation, whether through the internet, interaction with their elected State Senators and Representatives, active participation in advocacy and support groups involved with ASD, or through other means, both during the 2007 regular session of the Kentucky General Assembly and any subsequent session of the Kentucky General Assembly in which any such legislation is introduced.

## **CLOSING**

The positive reception of the HB 188 (2008) by the legislature provides advocates with sustained hope that there will be positive outcomes during the 2009 session. However, the 2009 session did not prove to be effective. HB 190 was introduced to support insurance coverage for the treatment of autism. While this bill passed the house with amendments that withdrew the coverage and inserted a study, the bill was not heard in the Senate. There continues to be a need for the Kentucky legislature to address the overarching needs of citizens with autism as have many states throughout the nation. An Autism bill, when passed and enacted into law will provide individuals with ASD and their families needed support and services that are currently not available in Kentucky.

President Obama throughout his campaign indicated his commitment to research and treatment of autism. Funds have been allocated to National Institute of Child Health and Human Development for such research. There is pending legislation at the national level for both educational and post school supports for individuals with autism.

[http://www.autismspeaks.org/inthenews/obama\\_insurance\\_mandate\\_bill.php](http://www.autismspeaks.org/inthenews/obama_insurance_mandate_bill.php) and <http://www.nichd.nih.gov>

The nation grant received by the Department of Education is a positive development. However if Kentuckians with autism are to receive needed services and supports, Kentucky must become more aggressive in seeking and providing grants, assure insurance coverage and dedicate a focused effort on autism.

## Appendix A



## Glossary of Terms

ABA	=	Applied Behavior Analysis
ARC	=	Admissions and Release Committee
ASD	=	Autism Spectrum Disorders
ASDAC	=	Autism Spectrum Disorders Advisory Consortium
CMS	=	Center for Medicaid and Medicare Services
DMHMR	=	Department of Mental Health and Mental Retardation
DMS	=	Department of Medicaid Services
DSM-IV-TR	=	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR®)
EPSDT	=	Early and Periodic Screening, Diagnosis and Treatment Program
ERISA	=	Employee Retirement Income Security Act
HCBS	=	Home and Community Based Services
IDEIA	=	Individuals with Disabilities Education Improvement Act
IEP	=	Individual Education Plan
IPE	=	Individualized Plans for Employment
ITP	=	Individualized Transitions Plans
KCDD	=	Kentucky Council on Developmental Disabilities
KEIS	=	Kentucky Early Intervention System
MCHAT	=	Modified Checklist for Autism in Toddlers
NRC	=	National Research Council
SIAC	=	State Interagency Council for Services to Children with an Emotional Disability

## Appendix B



## House Bill 296

1. **AN ACT relating to the Kentucky Commission on Autism Spectrum Disorders.**

Be it enacted by the General Assembly of the Commonwealth of Kentucky:

2. **SECTION 1. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO READ AS FOLLOWS:**

- (1) The Kentucky General Assembly finds that the various departments, agencies, and entities providing care and treatment to individuals with an autism spectrum disorder, otherwise known as ASD, often do so without the necessary collaboration or sharing of information on training, treatments, and services. The General Assembly declares that the purpose of Sections 1 and 2 of this Act is to establish:
- (a) A commission to develop and monitor the implementation of a comprehensive state plan for an integrated system of training, treatments, and services for individuals of all ages with an ASD; and
- (b) A timeline for implementing and monitoring the recommendations of the plan, as appropriate, in all geographic regions of the state.
- (2) As used in Sections 1 and 2 of this Act, "autism spectrum disorders" or "ASD" has the same meaning as "pervasive developmental disorders" in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). The term includes five (5) diagnostic subcategories:
- (a) Autistic disorder;
- (b) Asperger's disorder;
- (c) Pervasive disorder not otherwise specified;
- (d) Rett's disorder; and
- (e) Childhood disintegrative disorder.

3. **SECTION 2. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO READ AS FOLLOWS:**

- (1) There is hereby created the Kentucky Commission on Autism Spectrum Disorders, which shall consist of the following twenty-three (23) members who shall be initially appointed by July 1, 2005:
- (a) The secretary of the Cabinet for Health Services or his or her designee;
- (b) The secretary of the Cabinet for Families and Children or his or her designee;
- (c) The commissioner of the Department for Medicaid Services or his or her designee;

- (d) The director of the Kentucky Early Intervention System, Department for Public Health or his or her designee;
- (e) The commissioner of the Department for Mental Health and Mental Retardation Services or his or her designee;
- (f) The director of the Office of Aging Services or his or her designee;
- (g) The chair of the Council on Postsecondary Education or his or her designee;
- (h) The director of the Division of Exceptional Children Services or his or her designee;
- (i) The commissioner of the Department of Vocational Rehabilitation or his or her designee;
- (j) The commissioner of the Department of Insurance or his or her designee;
- (k) Two (2) nonvoting ex officio members from the House of Representatives, one (1) representing the majority party and one (1) representing the minority party, who shall be appointed by and serve at the pleasure of the Speaker of the House;
- (l) Two (2) nonvoting ex officio members from the Senate, one (1) representing the majority party and one (1) representing the minority party, who shall be appointed by and serve at the pleasure of the President of the Senate;
- (m) Four (4) professional ASD treatment providers, including at least one (1) mental health provider, one (1) physical health provider, and one (1) complex needs consultant from a special education cooperative, to be appointed by the Governor; and
- (n) Five (5) parents, including three (3) who, at the time of their appointment to the commission, have a child with an ASD who is under eighteen (18) years of age and two (2) who, at the time of their appointment to the commission, have a child with an ASD who is eighteen (18) years of age or older, to be appointed by the Governor.
- (2) In making appointments to the commission, the Governor shall ensure broad representation of Kentucky's citizens who are concerned with the health and quality of life of individuals with an ASD, may appoint individuals who are also members of the Kentucky Council on Developmental Disabilities, and shall consider candidates recommended by the Autism Spectrum Disorders Advisory Consortium of Kentucky.
- (3) Members shall serve without compensation, but shall be reimbursed for their actual expenses incurred in the performance of commission duties in accordance with KRS 45.101 and administrative regulations promulgated thereunder. Members of the commission shall serve until the commission ceases to exist, a successor has been appointed, or until removed for good cause.
- (4) The Cabinet for Health Services and the Cabinet for Families and Children shall provide staff and administrative support for the commission.
- (5) The chair of the commission shall be designated by the Governor and may be a member in addition to those listed in subsection (1) of this section. The chair of the commission shall

establish procedures for the commission's internal procedures.

(6) The commission shall meet at least three (3) times per year. The commission shall also meet as often as necessary to accomplish its purpose upon the call of the chair, the request of four (4) or more members, or the request of the Governor.

(7) The commission shall develop a comprehensive state plan for creating an integrated system of training, treatments, and services for individuals of all ages with an ASD. The commission shall utilize relevant data and research and consult with appropriate professionals, agencies, institutions, and organizations representing the private and public sectors, including the Kentucky Autism Training Center, to develop the state plan. The state plan shall include the following:

(a) An assessment of the diverse needs for services and supports for individuals with an ASD;

(b) Identification of state, federal, private, and any other appropriate funding sources;

(c) Development of a comprehensive training plan, which shall include the Kentucky Autism Training Center, to meet training needs;

(d) An analysis of standards for provider training and qualifications, best practice standards for services, and the need for additional service providers;

(e) An evaluation of health benefit plans and insurance coverage for the treatment of ASD;

(f) A plan for the identification of individuals of all ages with an ASD and for the creation of a statewide ASD registry;

(g) An analysis of program and service eligibility criteria;

(h) An assessment of the need for coordinated, enhanced, and targeted special education and treatment programs for children with an ASD; and

(i) A timeline for implementing and monitoring the recommendations of the plan statewide. The timeline shall include input from the following:

1. The Cabinet for Health Services;

2. The Cabinet for Families and Children;

3. The Department for Medicaid Services;

4. The Department for Public Health;

5. The Department for Mental Health and Mental Retardation Services;

6. The Kentucky Early Intervention System;

7. The Division of Exceptional Children Services;

8. The Department of Vocational Rehabilitation;

9. The Department of Insurance;

10. The Department of Education;

11. The Council on Postsecondary Education; and

12. Other appropriate agencies, professionals, institutions and organizations representing the public and private sectors, including the Kentucky Autism Training Center.

(8) Based upon the comprehensive state plan for an integrated system of training, treatment, and services for individuals of all ages with an ASD, the commission shall make recommendations regarding legislation, administrative regulations, and policies to the Governor and the General Assembly on the following:

(a) Needs for services and supports for individuals who have an ASD;

(b) Funding needs and sources, including state, federal, private, and any other appropriate funding sources;

(c) Training needs and a plan to implement a comprehensive training system, which shall include the Kentucky Autism Training Center;

(d) Standards for provider training and qualifications, best practice standards for services, and the need for additional providers;

(e) Goals for developing health benefit plans that provide insurance coverage for the treatment of ASD;

(f) A plan for the identification of individuals of all ages with an ASD and for the creation of a statewide ASD registry;

(g) Consistent program and service eligibility criteria;

(h) The need for coordinated, enhanced, and targeted special education and treatment programs for individuals with an ASD; and

(i) Strategies and timelines for establishing an accountable, cost efficient, and cooperative system of services that integrates and builds upon existing public and private agencies, programs, and resources.

(9) The commission shall submit the comprehensive state plan and recommendations to the Governor, the Kentucky Council on Developmental Disabilities, and the Legislative Research Commission by October 1, 2006, at which time the commission shall cease to exist unless reauthorized by the General Assembly.

(10) The Kentucky Council on Developmental Disabilities shall appoint a subcommittee, which shall include members of the commission, to monitor the implementation of the state plan as developed by the commission beginning October 1, 2006. The subcommittee shall prepare and the council shall submit a report to the Governor and Legislative Research Commission that assesses progress in the implementation of the state plan and that makes

recommendations on the need for modifications to the state plan as developed by the Kentucky Commission on Autism Spectrum Disorders. The subcommittee shall prepare and the council shall submit the report as it deems appropriate, but no less than biennially, until October 1, 2015.

4. **Section 3. KRS 194A.135 is amended to read as follows:**

- (1) **The Kentucky Council on Developmental Disabilities is created within the cabinet.**
- (2) **The Kentucky Council on Developmental Disabilities is established to comply with the requirements of the Developmental Disabilities Act of 1984 and any subsequent amendment to that act.**
- (3) **The members of the Kentucky Council on Developmental Disabilities shall be appointed by the Governor to serve as advocates for persons with developmental disabilities. The council shall be composed of twenty-six (26) members.**
- (a) **Ten (10) members shall be representatives of: the principal state agencies administering funds provided under the Rehabilitation Act of 1973 as amended; the state agency that administers funds provided under the Individuals with Disabilities Education Act (IDEA); the state agency that administers funds provided under the Older Americans Act of 1965 as amended; the single state agency designated by the Governor for administration of Title XIX of the Social Security Act for persons with developmental disabilities; higher education training facilities, each university-affiliated program or satellite center in the Commonwealth; and the protection and advocacy system established under Public Law 101-496. These members shall represent the following:**
  1. Department for Vocational Rehabilitation;
  2. Department for the Blind;
  3. Division of Exceptional Children, within the Department of Education;
  4. Office of Aging Services;
  5. Department for Medicaid Services;
  6. Department of Public Advocacy, Protection and Advocacy Division;
  7. University-affiliated programs;
  8. Local and nongovernmental agencies and private nonprofit groups concerned with services for persons with developmental disabilities;
  9. Department for Mental Health and Mental Retardation Services; and
  10. Department for Public Health, Division of Adult and Child Health.
- (b) **At least sixty percent (60%) of the members of the council shall be composed of**

persons with developmental disabilities or the parents or guardians of persons, or immediate relatives or guardians of persons with mentally impairing developmental disabilities, who are not managing employees or persons with ownership or controlling interest in any other entity that receives funds or provides services under the Developmental Disabilities Act of 1984 as amended and who are not employees of a state agency that receives funds or provides services under this section. Of these members, five (5) members shall be persons with developmental disabilities, and five (5) members shall be parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves. Six (6) members shall be a combination of individuals in these two (2) groups, and at least one (1) of these members shall be an immediate relative or guardian of an institutionalized or previously institutionalized person with a developmental disability or an individual with a developmental disability who resides in an institution or who previously resided in an institution.

- (c) **Members not representing principal state agencies shall be appointed for a term of three (3) years. Members shall serve no more than two (2) consecutive three (3) year terms. Members shall serve until their successors are appointed or until they are removed for cause.**
- (d) **The council shall elect its own chair, adopt bylaws, and operate in accordance with its bylaws. Members of the council who are not state employees shall be reimbursed for necessary and actual expenses. The cabinet shall provide personnel adequate to insure that the council has the capacity to fulfill its responsibilities. The council shall be headed by an executive director. If the executive director position becomes vacant, the council shall be responsible for the recruitment and hiring of a new executive director.**
- (4) **The Kentucky Council on Developmental Disabilities shall:**
  - (a) **Develop, in consultation with the cabinet, and implement the state plan as required by Part B of the Developmental Disabilities Act of 1984, as amended, with a goal of development of a coordinated consumer and family centered focus and direction, including the specification of priority services required by that plan;**
  - (b) **Monitor, review, and evaluate, not less often than annually, the implementation and effectiveness of the state plan in meeting the plan's objectives;**
  - (c) **To the maximum extent feasible, review and comment on all state plans that relate to persons with developmental disabilities;**
  - (d) **Submit to the secretary of the cabinet, the commissioner of the Department for Mental Health and Mental Retardation Services, and the Secretary of the United States Department of Health and Human Services any periodic reports on its activities as required by the United States Department of Health and Human Services and keep records and afford access as the cabinet finds necessary to verify the reports;**

- (e) **Serve as an advocate for individuals with developmental disabilities and conduct programs, projects, and activities that promote systematic change and capacity building;**
  - (f) **Examine, not less than once every five (5) years, the provision of and need for federal and state priority areas to address, on a statewide and comprehensive basis, urgent needs for services, supports, and other assistance for individuals with developmental disabilities and their families; and**
  - (g) **Prepare, approve, and implement a budget that includes amounts paid to the state under the Developmental Disabilities Act of 1984, as amended, to fund all programs, projects, and activities under that Act.**
- (5) The Kentucky Council on Developmental Disabilities shall appoint a subcommittee, which shall include members of the Kentucky Commission on Autism Spectrum Disorders, to monitor the implementation of the state plan as developed by the commission beginning October 1, 2006. The subcommittee shall prepare and the council shall submit the report as required under subsection (10) of Section 2 of this Act.

## Appendix C



## Members of the ASD Commission

## KENTUCKY COMMISSION ON AUTISM SPECTRUM DISORDERS

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<b>Office of Vocational Rehabilitation Executive Director</b> <b>Designee:</b> (Carol Estes) <a href="mailto:CarolH.Estes@ky.gov">CarolH.Estes@ky.gov</a>	<b>Beth Smith</b> 209 St. Clair St., 2 <sup>nd</sup> Fl. Frankfort, KY 40601 (502) 564-4440 <a href="mailto:Beth.Smith@ky.gov">Beth.Smith@ky.gov</a>	<b>Parent of Child with an ASD under 18 years of age</b>	<b>Virginia E. Gibbs</b> 601 Maryhill Lane Louisville, KY 40207 (502) 895-5363 <a href="mailto:bgibbs@turningpoint1.org">bgibbs@turningpoint1.org</a>
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## Appendix D



BR 121

5. **AN ACT relating to health insurance.**

Be it enacted by the General Assembly of the  
Commonwealth of Kentucky:

6. **➔SECTION 4. A NEW SECTION OF SUBTITLE 17A OF KRS CHAPTER 304 IS  
CREATED TO READ AS FOLLOWS:**

**As used in Sections 1 and 2 of this Act, unless  
the context requires otherwise:**

- (1) "Applied behavior analysis" means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior;
- (2) "Autism services provider" means any person, entity, or group that provides treatment of autism spectrum disorders;
- (3) "Autism spectrum disorder" means any of the pervasive developmental disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, including Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified;
- (4) "Diagnosis of autism spectrum disorders" means medically necessary assessment, evaluations, or tests to diagnose whether an individual has one (1) of the autism spectrum disorders;
- (5) "Habilitative or rehabilitative care" means professional, counseling, and guidance services and treatment programs, including applied behavior analysis, that are necessary to develop, maintain, and restore, to the maximum extent practicable, the functioning of an individual;
- (6) "Medically necessary" means any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist in accordance with accepted standards of practice and that will, or is reasonably expected to, do any of the following:
  - (a) Prevent the onset of an illness, condition, injury, or disability;
  - (b) Reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or
  - (c) Assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for the individuals of the same age;
- (7) "Pharmacy care" means medications prescribed by a licensed physician and any health-related services deemed medically necessary to determine the need or effectiveness of the medications;

- (8) "Psychiatric care" means direct or consultative services provided by a psychiatrist licensed in the state in which the psychiatrist practices;
- (9) "Psychological care" means direct or consultative services provided by a psychologist licensed in the state in which the psychologist practices;
- (10) "Therapeutic care" means services provided by licensed or certified speech therapists, occupational therapists, or physical therapists; and
- (11) "Treatment for autism spectrum disorders" includes the following care prescribed, provided, or ordered for an individual diagnosed with one (1) of the autism spectrum disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary:
  - (a) Habilitative or rehabilitative care;
  - (b) Pharmacy care;
  - (c) Psychiatric care;
  - (d) Psychological care; or
  - (e) Therapeutic care.

7. **➔SECTION 5. A NEW SECTION OF SUBTITLE 17A OF KRS CHAPTER 304 IS CREATED TO READ AS FOLLOWS:**

- (1) A health benefit plan shall provide coverage for the diagnosis of autism spectrum disorders and the treatment of autism spectrum disorders. To the extent that the diagnosis and treatment of autism spectrum disorders are not already covered by a health insurance policy, coverage under this section shall be included in health benefit plans that are delivered, executed, issued, amended, adjusted, or renewed within the state, or outside the state if insuring Kentucky residents, on or after thirty (30) days after the effective date of this Act. An insurer shall not terminate coverage, or refuse to deliver, execute, issue, amend, adjust, or renew coverage, to an individual solely because the individual is diagnosed with an autism spectrum disorders or has received treatment for an autism spectrum disorder.
- (2) Coverage under this section shall not be subject to any limits on the number of visits an individual may make to an autism services provider.
- (3) Coverage under this section may be subject to copayment, deductible, and coinsurance provisions of a health benefit plan that are no less favorable than those that apply to other medical services covered by the health benefit plan.
- (4) This section shall not be construed as limiting benefits that are otherwise available to an individual under a health benefit plan.
- (5) Except for inpatient services, if an individual is receiving treatment for an autism spectrum

disorder, an insurer shall have the right to request a review of that treatment not more than once every twelve (12) months unless the insurer and the individual's licensed physician or licensed psychologist agree that a more frequent review is necessary. The cost of obtaining any review shall be borne by the insurer.

(6) This section shall not be construed as affecting any obligation to provide services to an individual under an individualized family service plan, an individualized education program, or an individualized service plan.

8. ➔ **Section 6. KRS 18A.225 is amended to read as follows:**

(1) (a) The term "employee" for purposes of this section means:

1. Any person, including an elected public official, who is regularly employed by any department, office, board, agency, or branch of state government; or by a public postsecondary educational institution; or by any city, urban-county, charter county, county, or consolidated local government, whose legislative body has opted to participate in the state-sponsored health insurance program pursuant to KRS 79.080; and who is either a contributing member to any one (1) of the retirement systems administered by the state, including but not limited to the Kentucky Retirement Systems, Kentucky Teachers' Retirement System, the Legislators' Retirement Plan, or the Judicial Retirement Plan; or is receiving a contractual contribution from the state toward a retirement plan; or, in the case of a public postsecondary education institution, is an individual participating in an optional retirement plan authorized by KRS 161.567;
2. Any certified or classified employee of a local board of education;
3. Any elected member of a local board of education;
4. Any person who is a present or future recipient of a retirement allowance from the Kentucky Retirement Systems, Kentucky Teachers' Retirement System, the Legislators' Retirement Plan, the Judicial Retirement Plan, or the Kentucky Community and Technical College System's optional retirement plan authorized by KRS 161.567, except that a person who is receiving a retirement allowance and who is age sixty-five (65) or older shall not be included, with the exception of persons covered under KRS 61.702(4)(c), unless he or she is actively employed pursuant to subparagraph 1. of this paragraph; and
5. Any eligible dependents and beneficiaries of participating employees and retirees who are entitled to participate in the state-sponsored health insurance program;

(b) **The term "health benefit plan" for the purposes of this section means a health benefit plan as defined in KRS 304.17A-005;**

(c) **The term "insurer" for the purposes of this section means an insurer as defined in KRS 304.17A-005; and**

- (d) The term "managed care plan" for the purposes of this section means a managed care plan as defined in KRS 304.17A-500.**

(2) (a) The secretary of the Finance and Administration Cabinet, upon the recommendation of the secretary of the Personnel Cabinet, shall procure, in compliance with the provisions of KRS 45A.080, 45A.085, and 45A.090, from one (1) or more insurers authorized to do business in this state, a group health benefit plan that may include but not be limited to health maintenance organization (HMO), preferred provider organization (PPO), point of service (POS), and exclusive provider organization (EPO) benefit plans encompassing all or any class or classes of employees. With the exception of employers governed by the provisions of KRS Chapters 16, 18A, and 151B, all employers of any class of employees or former employees shall enter into a contract with the Personnel Cabinet prior to including that group in the state health insurance group. The contracts shall include but not be limited to designating the entity responsible for filing any federal forms, adoption of policies required for proper plan administration, acceptance of the contractual provisions with health insurance carriers or third-party administrators, and adoption of the payment and reimbursement methods necessary for efficient administration of the health insurance program. Health insurance coverage provided to state employees under this section shall, at a minimum, contain the same benefits as provided under Kentucky Kare Standard as of January 1, 1994, and shall include a mail-order drug option as provided in subsection (13) of this section. All employees and other persons for whom the health care coverage is provided or made available shall annually be given an option to elect health care coverage through a self-funded plan offered by the Commonwealth or, if a self-funded plan is not available, from a list of coverage options determined by the competitive bid process under the provisions of KRS 45A.080, 45A.085, and 45A.090 and made available during annual open enrollment.

- (b) The policy or policies shall be approved by the executive director of insurance and may contain the provisions he approves, whether or not otherwise permitted by the insurance laws.**

- (c) Any carrier bidding to offer health care coverage to employees shall agree to provide coverage to all members of the state group, including active employees and retirees and their eligible covered dependents and beneficiaries, within the county**

or counties specified in its bid. Except as provided in subsection ~~(19)~~~~(18)~~ of this section, any carrier bidding to offer health care coverage to employees shall also agree to rate all employees as a single entity, except for those retirees whose former employers insure their active employees outside the state-sponsored health insurance program.

- (d) Any carrier bidding to offer health care coverage to employees shall agree to provide enrollment, claims, and utilization data to the Commonwealth in a format specified by the Personnel Cabinet with the understanding that the data shall be owned by the Commonwealth; to provide data in an electronic form and within a time frame specified by the Personnel Cabinet; and to be subject to penalties for noncompliance with data reporting requirements as specified by the Personnel Cabinet. The Personnel Cabinet shall take strict precautions to protect the confidentiality of each individual employee; however, confidentiality assertions shall not relieve a carrier from the requirement of providing stipulated data to the Commonwealth.
- (e) The Personnel Cabinet shall develop the necessary techniques and capabilities for timely analysis of data received from carriers and, to the extent possible, provide in the request-for-proposal specifics relating to data requirements, electronic reporting, and penalties for noncompliance. The Commonwealth shall own the enrollment, claims, and utilization data provided by each carrier and shall develop methods to protect the confidentiality of the individual. The Personnel Cabinet shall include in the October annual report submitted pursuant to the provisions of KRS 18A.226 to the Governor, the General Assembly, and the Chief Justice of the Supreme Court, an analysis of the financial stability of the program, which shall include but not be limited to loss ratios, methods of risk adjustment, measurements of carrier quality of service, prescription coverage and cost management, and statutorially required mandates. If state self-insurance was available as a carrier option, the report also shall provide a detailed financial analysis of the self-insurance fund including but not limited to loss ratios, reserves, and reinsurance agreements.
- (f) If any agency participating in the state-sponsored employee health insurance program for its active employees terminates participation and there is a state appropriation for the employer's contribution for active employees' health insurance coverage, then neither the agency nor the employees shall receive the state-funded contribution after termination from the state-sponsored employee health insurance program.
- (g) Any funds in flexible spending accounts that remain after all reimbursements have been processed shall be transferred to the credit of the state-sponsored health insurance plan's appropriation account.
- (h) Each entity participating in the state-sponsored health insurance program shall provide an amount at least equal to the state contribution rate for the employer portion of the health insurance premium. For any participating entity that used

the state payroll system, the employer contribution amount shall be equal to but not greater than the state contribution rate.

- (3) The premiums may be paid by the policyholder:**

  - (a) Wholly from funds contributed by the employee, by payroll deduction or otherwise;**
  - (b) Wholly from funds contributed by any department, board, agency, public postsecondary education institution, or branch of state, city, urban-county, charter county, county, or consolidated local government; or**
  - (c) Partly from each, except that any premium due for health care coverage or dental coverage, if any, in excess of the premium amount contributed by any department, board, agency, postsecondary education institution, or branch of state, city, urban-county, charter county, county, or consolidated local government for any other health care coverage shall be paid by the employee.**
- (4) If an employee moves his place of residence or employment out of the service area of an insurer offering a managed health care plan, under which he has elected coverage, into either the service area of another managed health care plan or into an area of the Commonwealth not within a managed health care plan service area, the employee shall be given an option, at the time of the move or transfer, to change his or her coverage to another health benefit plan.**
- (5) No payment of premium by any department, board, agency, public postsecondary educational institution, or branch of state, city, urban-county, charter county, county, or consolidated local government shall constitute compensation to an insured employee for the purposes of any statute fixing or limiting the compensation of such an employee. Any premium or other expense incurred by any department, board, agency, public postsecondary educational institution, or branch of state, city, urban-county, charter county, county, or consolidated local government shall be considered a proper cost of administration.**
- (6) The policy or policies may contain the provisions with respect to the class or classes of employees covered, amounts of insurance or coverage for designated classes or groups of employees, policy options, terms of eligibility, and continuation of insurance or coverage after retirement.**
- (7) Group rates under this section shall be made available to the disabled child of an employee regardless of the child's age if the entire premium for the disabled child's coverage is paid by the state employee. A child shall be considered disabled if he has been determined to be eligible for federal Social Security disability benefits.**
- (8) The health care contract or contracts for employees shall be entered into for a period of not less than one (1) year.**
- (9) The secretary shall appoint thirty-two (32) persons to an Advisory Committee of State**

**Health Insurance Subscribers to advise the secretary or his designee regarding the state-sponsored health insurance program for employees. The secretary shall appoint, from a list of names submitted by appointing authorities, members representing school districts from each of the seven (7) Supreme Court districts, members representing state government from each of the seven (7) Supreme Court districts, two (2) members representing retirees under age sixty-five (65), one (1) member representing local health departments, two (2) members representing the Kentucky Teachers' Retirement System, and three (3) members at large. The secretary shall also appoint two (2) members from a list of five (5) names submitted by the Kentucky Education Association, two (2) members from a list of five (5) names submitted by the largest state employee organization of nonschool state employees, two (2) members from a list of five (5) names submitted by the Kentucky Association of Counties, two (2) members from a list of five (5) names submitted by the Kentucky League of Cities, and two (2) members from a list of names consisting of five (5) names submitted by each state employee organization that has two thousand (2,000) or more members on state payroll deduction. The advisory committee shall be appointed in January of each year and shall meet quarterly.**

- (10) Notwithstanding any other provision of law to the contrary, the policy or policies provided to employees pursuant to this section shall not provide coverage for obtaining or performing an abortion, nor shall any state funds be used for the purpose of obtaining or performing an abortion on behalf of employees or their dependents.**
  - (11) Interruption of an established treatment regime with maintenance drugs shall be grounds for an insured to appeal a formulary change through the established appeal procedures approved by the Office of Insurance, if the physician supervising the treatment certifies that the change is not in the best interests of the patient.**
  - (12) Any employee who is eligible for and elects to participate in the state health insurance program as a retiree, or the spouse or beneficiary of a retiree, under any one (1) of the state-sponsored retirement systems shall not be eligible to receive the state health insurance contribution toward health care coverage as a result of any other employment for which there is a public employer contribution. This does not preclude a retiree and an active employee spouse from using both contributions to the extent needed for purchase of one (1) state sponsored health insurance policy for that plan year.**
- (13) (a) The policies of health insurance coverage procured under subsection (2) of this section shall include a mail-order drug option for maintenance drugs for state employees. Maintenance drugs may be dispensed by mail order in accordance with Kentucky law.**
- (b) A health insurer shall not discriminate against any retail pharmacy located within the geographic coverage area of the health benefit plan and that meets the terms and conditions for participation established by the insurer, including price, dispensing fee, and copay requirements of a mail-order option. The retail pharmacy shall not be required to dispense by mail.**
  - (c) The mail-order option shall not permit the dispensing of a controlled substance**

classified in Schedule II.

- (14) The policy or policies provided to state employees or their dependents pursuant to this section shall provide coverage for obtaining a hearing aid and acquiring hearing aid-related services for insured individuals under eighteen (18) years of age, subject to a cap of one thousand four hundred dollars (\$1,400) every thirty-six (36) months pursuant to KRS 304.17A-132.
- (15) The policy or policies provided to state employees or their dependents pursuant to this section shall provide coverage for diagnosis of autism spectrum disorders and treatment of autism spectrum disorders consistent with Section 2 of this Act.
- (16) If a state employee's residence and place of employment are in the same county, and if the hospital located within that county does not offer surgical services, intensive care services, obstetrical services, level II neonatal services, diagnostic cardiac catheterization services, and magnetic resonance imaging services, the employee may select a plan available in a contiguous county that does provide those services, and the state contribution for the plan shall be the amount available in the county where the plan selected is located.
- ~~(17)~~~~(16)~~ If a state employee's residence and place of employment are each located in counties in which the hospitals do not offer surgical services, intensive care services, obstetrical services, level II neonatal services, diagnostic cardiac catheterization services, and magnetic resonance imaging services, the employee may select a plan available in a county contiguous to the county of residence that does provide those services, and the state contribution for the plan shall be the amount available in the county where the plan selected is located.
- ~~(18)~~~~(17)~~ The Personnel Cabinet is encouraged to study whether it is fair and reasonable and in the best interests of the state group to allow any carrier bidding to offer health care coverage under this section to submit bids that may vary county by county or by larger geographic areas.
- ~~(19)~~~~(18)~~ Notwithstanding any other provision of this section, the bid for proposals for health insurance coverage for calendar year 2004 shall include a bid scenario that reflects the statewide rating structure provided in calendar year 2003 and a bid scenario that allows for a regional rating structure that allows carriers to submit bids that may vary by region for a given product offering as described in this subsection:
- (a) The regional rating bid scenario shall not include a request for bid on a statewide option;
  - (b) The Personnel Cabinet shall divide the state into geographical regions which shall be the same as the partnership regions designated by the Department for Medicaid Services for purposes of the Kentucky Health Care Partnership Program established pursuant to 907 KAR 1:705;
  - (c) The request for proposal shall require a carrier's bid to include every county within the region or regions for which the bid is submitted and include but not be

restricted to a preferred provider organization (PPO) option;

- (d) If the Personnel Cabinet accepts a carrier's bid, the cabinet shall award the carrier all of the counties included in its bid within the region. If the Personnel Cabinet deems the bids submitted in accordance with this subsection to be in the best interests of state employees in a region, the cabinet may award the contract for that region to no more than two (2) carriers; and
- (e) Nothing in this subsection shall prohibit the Personnel Cabinet from including other requirements or criteria in the request for proposal.

~~(20)~~~~(19)~~ Any fully insured health benefit plan or self-insured plan issued or renewed on or after July 12, 2006, to public employees pursuant to this section which provides coverage for services rendered by a physician or osteopath duly licensed under KRS Chapter 311 that are within the scope of practice of an optometrist duly licensed under the provisions of KRS Chapter 320 shall provide the same payment of coverage to optometrists as allowed for those services rendered by physicians or osteopaths.

~~(21)~~~~(20)~~ Any fully insured health benefit plan or self-insured plan issued or renewed on or after July 12, 2006, to public employees pursuant to this section shall comply with the provisions of KRS 304.17A-270 and 304.17A-525.

~~(22)~~~~(21)~~ Any full insured health benefit plan or self insured plan issued or renewed on or after July 12, 2006, to public employees shall comply with KRS 304.17A-600 to 304.17A-633 pertaining to utilization review, KRS 205.593 and 304.17A-700 to 304.17A-730 pertaining to payment of claims, KRS 304.14-135 pertaining to uniform health insurance claim forms, KRS 304.17A-580 and 304.17A-641 pertaining to emergency medical care, KRS 304.99-123, and any administrative regulations promulgated thereunder.

9. ➔Section 7. The following KRS section is repealed:

**304.17A-143 Coverage for treatment of autism in children -- Limitation -- Definitions.**

## Appendix E



### Definitions of Best Practices Used by the Department of Mental Health and Mental Retardation

**"Best Practices" is a continuum of practices and programs ranging from promising to evidence-based to science -based**

**Promising Practice** means a practice that:

1. Incorporates the philosophy, values, characteristics and indicators of other positive and effective public health interventions.
2. Is based on guidelines, protocols, standards or preferred practice patterns that have been proven to lead to effective public health outcomes.
3. Is a process of continual quality improvement that:
  - i. Accumulates and applies knowledge about what is working and not working with the practice in different situations and contexts.
  - ii. Continually incorporates lessons learned, feedback, and analysis to lead toward improvement/positive outcomes.
  - iii. Allows for and incorporates expert review, feedback, and consensus from the public health field.
4. Has an evaluation component in place to move toward demonstration of effectiveness. It does not yet, however, have sufficient evaluation data available to demonstrate positive outcomes.

**Evidence-Based Practice** means a practice that has been or is being evaluated, and it:

1. Has some quantitative and qualitative data showing positive outcomes, but does not yet have sufficient research or replication-related data to support general positive public health outcomes.
2. Has been subject to expert/peer review that has determined that this particular approach or strategy has a significant level of evidence of effectiveness in public health research literature.

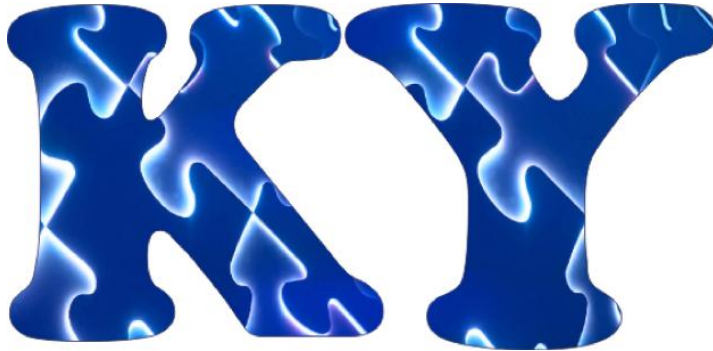
**Science-Based Practice** means a practice that results from a rigorous process of research and evaluation that indicates effectiveness in improving public health outcomes for a target population. A science-based practice:

1. Has been evaluated using a theory-based research methodology.
2. Was implemented as intended in order to clearly link positive effects to the program/practice being evaluated and not to extraneous factors.
3. Has been reviewed and substantiated by experts in the public health field according to predetermined standards of empirical research.
4. Is replicable, and produces desirable results in a variety of settings.

Source: [http://mhmr.ky.gov/kdmhmrs/best\\_practices.asp](http://mhmr.ky.gov/kdmhmrs/best_practices.asp);

Last Updated 4/27/2006 4:07:53 PM.

## Appendix F



## Recommendation Grid

Number	Recommendation	Action	Status
1	Creation on Supports for Individuals with Autism Spectrum Disorders Program	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008- Legislation successfully passed the House with floor amendment, was not heard in Senate.
2	Creation of an Advisory Board for the Program	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008 – HB 188 was amended in House; removed stipulation.
3	Developmental of a waiver for support for individuals with ASD	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008 – HB 188 was amended in House; removed stipulation.
4	Develop a non-waiver program for those who do not meet Medicaid eligibility	2007 – Not addressed 2008- Not addressed	
5	Full funding for First Steps	2007 – Not Addressed 2008 – Not Addressed	
6	Interagency agreement between the Program and the Department of Education (DOE)	2007 – Legislation introduced HB 109 (amended to include a member from DOE on the program advisory board) 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate 2008 -HB 188 was amended in House; removed stipulation.
7	Well baby checks, 18-24 months, age 4, 6 thru 17 for ASD – treatment within 90 days	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	2007 -Legislation successfully passed the House was received in the Senate; was not heard in the Senate. 2008 – HB 188 was amended in House; removed stipulation.
8	Change insurance regulations to prohibit deductibles, coinsurance, or co-payments for covered ASD health benefits and other changes to promote equal access	2007 – Legislation introduced HB 91  2008 – Not	2007 -Legislation posted to committee; not heard during session

		Addressed	
9	Change insurance regulations to prohibit deductibles, coinsurance, or co-payments for covered ASD health benefits and other changes to promote equal access	2007 – Legislation introduced HB 91 2008 – Not Addressed	2007 -Legislation posted to committee; not heard during session
10	State wide registry	2007 - Not addressed 2008 – Not Addressed	
11	State wide advocacy request Kentucky federal delegation to amend federal Employee Retirement Income Act (ERISA) to cover insured with ASD	2007 - Not addressed 2008 – Not Addressed	
12	Develop a training plan for professional and paraprofessionals under contract with KATC, develop regional centers, provide assessment, treatments and research	2007 – Legislation introduced HB 109 2008 – Legislation introduced HB 188	<p>2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate. 2008 – HB 188 was amended in House; removed stipulation.</p> <p>Kentucky has been selected by the National Professional Development Center on Autism Spectrum Disorders to be one of only three states to receive technical assistance related to autism, which affects more than 2,300 school-aged children statewide.</p> <p>The Kentucky Department of Education (KDE) and the Kentucky Autism Training Center (KATC), located at the University of Louisville, partnered on the grant application. KDE and KATC will work in collaboration with the FPG Child Development Institute at the University of North Carolina at Chapel Hill, the Waisman Center at the University of Wisconsin-Madison and the M.I.N.D. Institute at the University of California Davis Medical School to implement the two-year project. KDE and KATC also will partner with the statewide network of Special Education Cooperatives and Early Childhood Regional Training Centers, Kentucky’s Infant-Toddler Program (First Steps), the Parent Training and Information Network (KY-SPIN), the Kentucky Council on Developmental Disabilities, institutions of higher education and many other state partners.</p> <p>The purposes are to:</p> <ul style="list-style-type: none"> <li>• increase the number of highly qualified personnel (particularly</li> </ul>

			<p>teachers and practitioners) serving children and youth with ASD in Kentucky</p> <ul style="list-style-type: none"> <li>• establish a sustainable system of professional development in evidence-based practices in ASD</li> <li>• provide technical assistance support for early childhood practitioners, educational leaders, teachers and school-based personnel</li> </ul> <p>Additional funds were not awarded at the state or federal level</p>
13	The Program to develop a comprehensive network, including interagency transition teams for all individual with ASD	<p>2007 – Legislation introduced HB 109</p> <p>2008 – Legislation introduced HB 188</p>	<p>2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate.</p> <p>2008 – HB 188 was amended in House; removed stipulation.</p>
14	Establish a permanent subcommittee of the Interim Joint Committee on Health and Welfare of the KY General Assembly	<p>2007 -Not addressed</p> <p>2008 – Not Addressed</p>	
15	Department of Education update the statewide technical assistance manual on Autism	<p>2007 -Not addressed</p> <p>2008 – Grant application.</p>	<p>2007 -Legislation successfully passed the House was received in the Senate was not heard in the Senate.</p> <p>2008 – HB 188 was amended in House; removed stipulation.</p> <p>Kentucky has been selected by the National Professional Development Center on Autism Spectrum Disorders to be one of only three states to receive technical assistance related to autism, which affects more than 2,300 school-aged children statewide.</p> <p>The Kentucky Department of Education (KDE) and the Kentucky Autism Training Center (KATC), located at the University of Louisville, partnered on the grant application. KDE and KATC will work in collaboration with the FPG Child Development Institute at the</p>

			<p>University of North Carolina at Chapel Hill, the Waisman Center at the University of Wisconsin-Madison and the M.I.N.D. Institute at the University of California Davis Medical School to implement the two-year project. KDE and KATC also will partner with the statewide network of Special Education Cooperatives and Early Childhood Regional Training Centers, Kentucky's Infant-Toddler Program (First Steps), the Parent Training and Information Network (KY-SPIN), the Kentucky Council on Developmental Disabilities, institutions of higher education and many other state partners.</p> <p>The purposes are to:</p> <ul style="list-style-type: none"> <li>• increase the number of highly qualified personnel (particularly teachers and practitioners) serving children and youth with ASD in Kentucky</li> <li>• establish a sustainable system of professional development in evidence-based practices in ASD</li> <li>• provide technical assistance support for early childhood practitioners, educational leaders, teachers and school-based personnel</li> </ul> <p>Additional funds were not awarded at the state or federal level</p>
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